

Introduction

In 2018, the Centers for Disease Control and Prevention (CDC) published the Early Hearing Detection and Intervention (EHDI) program's annual data reporting 1.7 per 1,000 newborns were documented as receiving early identification as congenitally deaf or hard of hearing (DHH). This number increases to 5 per 1,000 children for school aged children. When DHH children receive early identification and timely and appropriate intervention services, they demonstrate better outcomes than children identified later in the areas of vocabulary development, receptive language, expressive language, and social-emotional development.

The Arkansas Department of Health's (ADH) Infant Hearing Program (IHP) proposes to continue building and improving a statewide system of care to ensure children who are DHH are identified through newborn, infant, and early childhood hearing screenings; receive timely diagnosis; and enroll in appropriate intervention to optimize language, literacy, cognitive, and social-emotional development. This system will continue providing a coordinated infrastructure to ensure all newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in early intervention (EI) by 6 months of age in addition to reducing loss to follow-up/documentation. The project goals will be achieved through the following activities:

- (1) Assessing infrastructure, including data collection and reporting, to ensure a capacity to support hearing screening for children up to age three;
- (2) Maximizing partnerships for referral, training, and information sharing with various stakeholders, organizations, and programs that include but are not limited to Arkansas' health professionals, service providers, birthing facilities, and state organizations;
- (3) Identifying key partners who can help address gaps in the EHDI system;
- (4) Engaging stakeholders through a biannual state EHDI advisory committee meeting to advise on programs, objectives, and strategies throughout the project period;
- (5) Increasing diversity and inclusion in the EHDI system to ensure activities address the needs of the state's entire population;
- (6) Promoting the IHP website for families and professionals;
- (7) Engaging, educating, and training health professionals and service providers on key aspects of the EHDI system through outreach and education activities;
- (8) Increasing family support and engagement activities for families with children who are DHH, as well as including adults who are DHH as mentors and partners throughout the EHDI system; and

(9) Facilitating coordination of care and services for families and children who are DHH.

These activities will drive efforts to increase the number of infants completing a hearing screen by one month of age, a diagnostic audiological evaluation by three months of age for those who do not pass the initial screen, and enrollment in EI services by six months of age, if identified as DHH. Additionally, the program will strive to increase the number of families enrolled in family-to-family support services by six months of age and DHH adult-to-family support services by nine months of age.

Needs Assessment

According to the 2010 United States Census, Arkansas held a total population of 2,915,918 with 56 people per square mile. Of the total population, 79.1% were Caucasian, 15.7% African American, 1% American Indian, 1.7% Asian, .4% Pacific Islander, 7.7% Hispanic or Latino, and 2.2% represented two or more races. The majority of the state is statutorily rural, impoverished, and medically underserved as defined by the Health Resources and Services Administration (HRSA). The state is composed of mountains, valleys, dense woodlands, and fertile plains. Arkansas is a key player in the cattle, poultry, swine, and egg production industries, as well as fruit, vegetable, and soybean cultivation. The densely wooded areas around the state also play a vital role in the harvesting and production of timber products, including lumber and paper. These industries and opportunities for migrant farming have drawn a significant number of immigrant workers, including undocumented immigrant workers. A study published by the Urban Institute reports that Arkansas ranked fourth among the states in immigrant population growth from 2000-2010, with the foreign-born population increasing by 83%. As the immigrant population has grown, so has the number of undocumented immigrants flocking to Arkansas for positions working in the state's top industries, migrant farming, and other available opportunities.

In addition, Arkansas ranks 46th in the nation for poverty rates at 18.1% or one out of every 5.5 people. The percentage of Arkansas residents living in poverty is the eighth highest in the nation, while median household income in the state is the third lowest in the United States, according to 2018 research published by the Arkansas Economic Development Institute. Throughout Arkansas, one of the main social problems is generational poverty, in which at least two generations of persons in the same family live at or below the federal poverty level. Parents living in poverty with their children may not have the opportunity to learn the skills necessary to manage their households and utilize their resources to optimum levels. The effects of poverty are statistically linked to negative outcomes for children including low birth weight, academic failure, and emotional distress. These statistics lead to further problems affecting the population including lack of education, lack of transportation, and language barriers which may impact parents' ability to obtain timely initial hearing screenings, diagnostic testing, and enrollment in quality EI services.

Access to health care and preventative health services varies widely in the state. The metropolitan area of the Central Region is home to a surplus of health services for women and children. However, despite the availability of services, low-income families are faced with obstacles reaching these services. These obstacles include parents understanding next steps after

their infant does not pass a hearing screening, transportation to services, and medical subspecialists' understanding the importance of a timely rescreening, referral for diagnostic testing, and enrollment in EI services.

Arkansas' IHP is a comprehensive infrastructure composed of a team of individuals working to improve the EHDI system in the state. The IHP also includes an online EHDI-Information System encompassed as part of the Electronic Registration of Arkansas Vital Records (ERAVE), which is ADHs' secure, online database for submitting and managing reports of vital events including deaths, infant hearing records, and births. The state's most recent goals have been to increase the number of newborns and infants who receive timely screening, diagnosis, referral to EI, and enrollment in EI services if identified as DHH, per the Joint Committee on Infant Hearing (JCIH) recommended practice guidelines. The information reported by Arkansas' IHP in the 2017 Hearing Screening and Follow-up Survey highlighted there were at least 35,968 occurrent births reported to the EHDI system. Out of the total births reported:

- 35,588 received hearing screenings;
- 95% of screenings were performed by the time the infant was one month of age;
- 32% of infants were diagnosed with confirmed hearing loss by three months of age; and
- 66% of infants with a confirmed diagnosis were referred to Part C services by six months of age. However, only 2% were enrolled in Part C services by six months of age, and 16% were receiving Non-Part C services by six months of age.

The IHP developed a partnership, supported by a memorandum of agreement (MOA), with Arkansas Hands & Voices (AR H&V), a statewide, family-based organization providing family support to families/parents/caregivers of children who are DHH. AR H&V is an unbiased parent support group composed of families with children who are DHH. These parents are able to connect with families with newly diagnosed DHH children to assist them in navigating the system.

The IHP plans to address the many needs and obstacles facing the state's diverse populations throughout the course of this project to ensure each child receives the quality care they deserve. The IHP will be steadfast on the course to increase the number of infants and children 0-3 years of age receiving quality hearing screenings, diagnostic testing, and EI services. The program will continuously seek to identify key stakeholders, organizations, and programs that can play an active role in identifying and addressing the needs of infants and children who are DHH and their families. The IHP will work to identify and collaborate with organizations and programs that address specific needs of underserved populations in Arkansas as well. These collaborations will ensure cultural sensitivity, understanding, and culturally specific information will reach the intended populations and promote an increase in services to the target populations.

In addition, a problem area the IHP intends to focus on during the project period includes loss to follow-up/documentation. Data collected from 2017 concludes that 17% of all children diagnosed were enrolled in either Part C or Non-Part C EI services by 6 months of age, with only 2% being enrolled in Part C services. Significant focus will be placed on meeting with Part C and

Non-Part C providers to address gaps in the system and devise ways of overcoming obstacles preventing or interfering with reducing the loss to follow-up/documentation issue.

If awarded, the IHP's focus will be placed on leading efforts to:

- Engage and coordinate all stakeholders in the state EHDI system to meet the goals of this project;
- Engage, educate, and train health professionals and service providers in the EHDI system per recommended practice guidelines;
- Strengthen capacity to provide family support and engage families with children who are DHH, as well as adults as mentors and partners who are DHH throughout the EHDI system; and
- Facilitate improved coordination of care and services for families and children who are DHH.

The target population for this focus will be all infants and children ages 0-3 statewide, as well as stakeholders, including but not limited to, clinicians who deliver pediatric primary care, pediatric specialists, nurses, EI service providers, audiologists, birthing facilities, parents/families of DHH children, and DHH individuals.

Methodology

The IHP proposes to implement efforts to engage all stakeholders in the EHDI system to improve developmental outcomes for children who are DHH. These efforts include ensuring every birthing facility, healthcare provider, and EI service provider follows the 1-3-6 recommended practice guidelines identified by the JCIH. Through training, distribution of educational materials, media campaigns, and other ventures the IHP will ensure all newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in EI services by 6 months of age. Additional efforts include reducing loss to follow-up by developing a continuum of care to address gaps in the EHDI system that lead to healthcare providers and early intervention specialists failing to report services provided to the children into ERAVE.

MOA with key stakeholders will continue to be developed annually to specify each organization's role in the EHDI program. These agreements include providing screening and diagnostic evaluation in underserved areas of the state, family support services, and promoting developmental screening/monitoring as outlined in the MOAs and letters of support included in *Attachments 4 and 7* respectively. The IHP will specifically work closely with Part C and Non-Part C organizations providing EI services to ensure a coordinated referral and enrollment guaranteeing consistent outcomes for children who are DHH.

The IHP has been working to identify problems and risks in the EHDI system, leading to loss to documentation. The IHP will continue to perform this task as well as begin developing and testing, through Plan, Do, Study, Act (PDSA) methodology, ways to reduce the identified

problem of loss to documentation. Furthermore, once quality improvement testing has proven effective, the IHP will work with key stakeholders to develop standard best practices particular to the state of Arkansas and assist in widespread adoption across all disciplines. Key partnerships for this cycle include collaborating with birthing facilities, hearing screening providers, pediatric medical subspecialists, maternal child health (MCH) programs, Women, Infants, and Children (WIC) program, Early Head Start, AR H&V, First Connections, Non-Part C organizations, Arkansas School for the Deaf Statewide Services, and additional organizations identified throughout the course of the project. By the end of year 1, the IHP will complete an assessment of current partnerships and identify key partners who can help address gaps in the state EHDI system. These partnerships will be reviewed annually and representatives from these organizations will participate on the multidisciplinary advisory board and stakeholder subcommittees in addition to parents of children who are DHH and adults who are DHH. The advisory board will meet at least biannually to advise on programs, objectives, and strategies throughout the project period and subcommittees will meet as needed. By the end of year 2, the IHP will develop a plan to address diversity and inclusion in the EHDI system to ensure EHDI system's activities are inclusive and address the needs of all populations served. Identified key partners to assist in the IHP's efforts include the ADH Office of Minority Health and Health Disparities, Arkansas Mexican Consulate, and Partners for Inclusive Communities. These key partners will be engaged to assist the IHP in this effort as state experts in addressing disparities and ensuring inclusiveness.

A partnership is being developed with the Leadership Education In Neuro-Developmental Disabilities (LEND) program to provide opportunities to work with students to determine potential quality improvement studies, conduct networking activities, participate in statewide child development functions, provide education and training on the 1-3-6 recommendations, and provide education on the need for hearing screening up to age 3 for infants who pass a newborn screen but later develop hearing loss. LEND will also actively participate with the Universal Hearing Screening, Tracking and Intervention Advisory Board and IHP learning communities. The IHP will continue quarterly learning community meetings to facilitate a platform for developing and evaluating strategies for continuous quality improvement. The learning communities will be facilitated to include trainings by providers, presentations from parents of a child who are DHH, adults who are DHH, and other activities to improve the developmental outcomes for children who are DHH. Through all of the activities provided and participants educated, the IHP will be evaluating each step to ensure an increase in the number of children screened, diagnosed, and enrolled in EI services, as well as an increase in the number of families enrolled in family-to-family support services. The activities will most certainly have an impact in supporting systems of care so families with newborns, infants, and young children who are DHH receive appropriate and timely services to optimize their language, literacy, and social-emotional development. The IHP's Logic Model, *Attachment 1.A*, provides a diagram outlining the links among program elements defining the scope of the project and desired outcomes.

Increased implementation of the AR H&V's Guide By Your Side program will improve support efforts statewide to engage families throughout all project levels. Outreach and education will be performed to inform families about opportunities to be involved in different roles within the EHDI system. AR H&V's advocacy education program (ASTra) will provide opportunities to collaborate with leaders and policy makers in addressing challenges and providing solutions to

address gaps in the EHDI system. A variety of communication methods listed in the Work Plan, *Attachment 1*, will be utilized to reach families including but not limited to social media, videos, and other communication platforms.

Currently, the IHP works closely with an Early Head Start program. The IHP's audiologist provides audiological services to assist in completing hearing screenings and training for staff to complete screenings in the facility for children 0-3 years. Plans are currently being made through meetings and discussions with the Arkansas Head Start Association to provide trainings and educations to all early head start programs in the state.

The IHP will continue efforts with WIC to increase access to families needing assistance through the program by providing updated contact information, educating families on the importance of timely screening as part of developmental monitoring, and completing a referral to the IHP for WIC participants with children who did not pass the hearing screening. These efforts will coincide with ADH's efforts to promote developmental screening education as part of the CDC's Learn the Signs Act Early campaign.

Lastly, the IHP will coordinate with the National Center for Hearing Assessment Management (NCHAM) to receive technical assistance on conducting and tracking quality improvement activities. NCHAM materials such as roadmaps, scripts for communicating results with families, and educational webinars for health care professionals will be shared with target populations to increase the recipient's knowledge.

The IHP will update, maintain, and promote the program's webpage (www.ar.healthyhearing.com) to ensure the webpage is user friendly with accessible, evidenced based, culturally appropriate information for families. Comprehensive, evidence-based information will also be available for professionals. Surveys will be utilized to address the effectiveness and user-friendliness of the website.

Outreach and trainings will be provided to health professionals and service providers. Topics of outreach and trainings will include providing guidance on how to follow the 1-3-6 recommendations; the need for hearing screenings up to age 3 to address the needs of children who later develop hearing loss after passing their initial newborn hearing screening; the benefits of a patient/family-centered medical home and family engagement in the care of the child; and the importance of communicating accurate, comprehensive, up-to-date, evidence-based information to allow families to make important decisions for their children in a timely manner. These educational activities will include webinars, workshops, presentations at professional conferences, professional newsletter article submissions, web-based content, social media, e-blast sent via listserves, and other communication channels.

Funding will provide the IHP with the resources to have a significant public health impact and support the Family Health Branch's efforts to address MCH national performance measures (i.e. developmental screening). Input from stakeholders participating in the EHDI system will allow the IHP to provide quality output in the form of trainings and educational

presentations to families and those working in the EHDI system. Pre and Post Assessments will be utilized to evaluate current belief systems and training methods in efforts to track increases in knowledge of participants.

Work Plan

A work plan providing detailed information regarding the measures and timeframes relating to conducting each activity is included in *Attachment 1*. Each goal discussed in the methodology section is accompanied by objectives, activities, timelines, responsible parties (including partners), and evaluation methods are presented in chart form.

Resolution of Challenges

One of the primary challenges for implementing this project is reaching pediatric medical subspecialists (i.e. pediatricians, family practitioners, audiologists, etc.) and early intervention service professionals who provide services to children who are DHH. Due to the highly rural nature of the state, access to pediatricians, pediatric audiologists, and high quality early intervention service providers for children who are DHH are limited outside of the metropolitan areas of the state. Additionally, due to the high rate of poverty and lack of financial resources, many families lack the transportation required to access the services available near the state's capital and the few other urban areas of the state. This lack of transportation leads to parents being unable to follow-up and meet the recommended 1-3-6 practice guidelines promoted by JCIH. Moreover, primary care physicians are not always familiar with the JCIH recommended best practice guidelines, due to the low incidence of DHH children served in rural areas. As a result, primary care physicians in rural areas can experience difficulties in instructing families in appropriate next steps per 1-3-6.

To overcome these challenges, the IHP proposes to detect additional ways to identify and engage healthcare professionals in rural areas providing services for children 0-3 years of age. The IHP is working to solidify partnerships with the Arkansas Academy of Pediatrics, Arkansas Academy of Family Physicians, Arkansas Academy of Audiology, and other governing and regulating associations to offer professional development so training can be provided through individual agreements developed between those organizations and IHP. Working with the Child and Adolescent Health Medical Director, a family practitioner, and the IHP Audiologist will permit peer-to-peer education opportunities for providers statewide through the development and distribution of best practices, offering trainings via web conference, and in-person trainings/presentations. These agreements will be developed with the goal of engaging, educating, and training health professionals and service providers on the EHDI system; 1-3-6 recommended best practice guidelines; the need for hearing screening up to age 3; the benefits of a family-centered medical home; and the importance of communicating comprehensive, up-to-date, evidence-based information to families to facilitate the decision-making process. Current agreements with First Connections and the Arkansas School for the Deaf, will be assessed and revised as needed to facilitate improved coordination of care and services for children who are DHH and their families through the development of mechanisms for formal communication, training, referrals, and data sharing.

Another challenge the IHP plans to address during the proposed project period, is the parents' lack of awareness of the importance of EHDI. Parent feedback indicates many parents are unaware a hearing screen occurs after birth, they did not receive their child's hearing screen results, and next steps were not clearly communicated prior to hospital discharge or by the child's primary care physician. Parents also indicate they would like connections to family support if their child is identified as DHH.

Steps to address these obstacles include continued development of an integrated health information system, best practice guidelines particular to the needs of Arkansas, and implementation of evidence based strategies for data sharing and linkage will allow important health information to be consolidated and shared amongst professionals involved in the child's healthcare needs. This care coordination promotes parents as partners in decision-making and fosters ongoing, coordinated care in the child's medical care and beyond. Additionally, the IHP will place a stronger focus on outreach efforts and trainings to strengthen the capacity to provide family support and engage families with children who are DHH. These efforts will be executed through social media campaigns and promotions, webinars, workshops, presentations at association meetings, publications in newsletters, web-based content, e-blasts via listserves, and other communication and educational activities as appropriate.

Evaluation and Technical Support Capacity

The IHP will collect data using the web based ERAVE database. Users entering information into ERAVE include birthing facilities, primary care physicians, audiologists, Part C, and IHP staff. ERAVE tracks the hearing screening results, diagnosis, and early intervention services of all infants. As such, the IHP will have the capabilities to evaluate unduplicated data from various populations throughout the state using the database. ERAVE is capable of producing numerous reports upon demand to assist the IHP staff with tracking and evaluating data collection. These reports will be used to monitor program performance. IHP staff will evaluate ERAVE reports weekly, monthly, and quarterly. IHP utilizes tracking materials (pre/post assessments, evaluations, surveys, etc.), outreach reports, and attendance records to assist in the evaluation of activities designed to ensure goals and objectives are met. Stakeholders meetings, including advisory board, learning community, and workgroup meetings, will be evaluated by tracking materials and monitoring attendance records to show improvements in the diversity and quantity of participants.

The IHP staff is experienced in collecting and analyzing data as seen in *Attachment 3*. Additional training and technical assistance will be requested from the HRSA National Resource Center program recipient. Analysis of stated materials will allow IHP to modify processes at appropriate times aiding program efficiency. The IHP will continue utilizing appropriate tracking materials (i.e. PDSA data analysis) to identify improvements or deficiencies in the project. Quality Improvement (QI) progress will be tracked and reviewed monthly to determine performance in accordance with measures for each objective as identified on the work plan, *Attachment 1*. Findings will be shared with partners during stakeholder meetings, published in the annual report provided to the state legislature's Joint Interim Committee of Public Health,

Labor, and Welfare, and as part of the program's publications disseminated and posted on the website.

Goals and objectives are aimed at promoting and improving the EHDI program. As such, the IHP staff will utilize PDSA methodology to evaluate the progress of each goal throughout the project period. Staff will implement small tests of change when developing new educational materials, revising protocols, and identifying behavior change amongst parents and pediatric medical subspecialists providing services to children who are DHH. Results of QI findings will be shared with stakeholders and implemented for systems of change and further development and reporting.

Organization Information

ADH was established in 1913 and has a mission "to protect and improve the health and well-being of all Arkansans". Services are provided statewide from the central office in Little Rock and 92 local health units are located in the state's 75 counties. The agency is divided into Centers, which oversee the day-to-day operations of the various departments. The IHP is located within the Center for Health Advancement's Family Health Branch in the Child and Adolescent Health Section as outlined on the Organization Chart included as *Attachment 5*. This Center's focus is to promote the health of Arkansas through public health policy prevention services and evidence-based health promotion. The mission of IHP is "all infants born in Arkansas will be screened and treated for hearing loss in accordance with Arkansas law and JCIH recommended practice guidelines". Currently the program is collaborating and developing plans with AR H&V, EI service providers, Office of Minority Health & Health Disparities, Arkansas Head Start Association, and additional partners to assist in improving data collection and reporting of hearing screenings for children up to 3 years of age. Throughout this project period, the IHP will continue working to reduce loss-to-follow up/documentation of children who are DHH by monitoring data in ERAVE and continuing/developing new partnerships with stakeholders of the EHDI system. Personnel qualified to carry out this project include the Follow-up Coordinator and Health Program Specialist, along with additional IHP staff, as outlined in the Staff Plan provided as *Attachment 2*. The IHP is more than capable of supporting various populations culturally and linguistically by collaborating with identified partners, both inside and outside of the agency to meet program expectations.

Infant hearing screenings and reporting was mandated by Arkansas Act 1559 of 1999 by Arkansas state legislature. Through this act, the IHP continues to produce significant results by collaborative efforts and vital input from stakeholders. Act 1559 also created the Universal Newborn Hearing Screening, Tracking, and Intervention Advisory Board. This advisory board is an active group of stakeholders that observe the needs of the EHDI system and make recommendations on solutions by implementing quality improvement strategies. The committee includes clinicians, parents of children who are DHH, individuals who are DHH, and IHP staff. The IHP receives funding from ADH, HRSA, CDC, and MCH to continually maintain and improve the EHDI system while working towards sustainability. This collaborative funding has allowed the program to grow and solidify services. The agency continues to increase support for the program via state newborn screening funds in addition to MCH funds. The IHP staff are

always seeking to identify new external funding opportunities in order to sustain the program in part or total completion.

To properly account for the federal funds and document all costs to avoid audit findings the ADH uses the Arkansas Administrative Statewide Information System (AASIS) to comply with and support policies and procedures promulgated by the Arkansas Department of Finance & Administration Offices of Budget, Personnel Management, Accounting, State Procurement and the Division of Employee Benefits. AASIS is a basic SAP system configured to carry out the business processes of Arkansas State Government. The finance module contains collective accounting records and budgetary controls. The existing financial management policies and procedures meet the requirements listed in the grant application.

Budget Narrative

The IHP requests funds to fulfill the goals and objectives previously stated in the work plan and methodology. Funding will support two personnel devoted solely to the project to complete all activities as described and QI projects. The budget also includes travel expenses for one staff member to attend the Annual EHDI Meeting. Additionally, 25% of funding will be utilized to support AR H&V's efforts to provide family-to-family support activities (including the Guide By Your Side and ASTra programs), connecting children who are DHH and their families to an adult who is DHH, and supporting travel expenses for one parent to attend the Annual EHDI Meeting. The attached budget narrative provides a detailed justification of how proposed expenditures will support the achievement of the proposed goals and objectives. Budgets for year 2, 3, and 4 will reflect minimal increases in personnel costs (salary and fringe), contracts (specifically related to ERAVE maintenance allowing data collection). Costs for travel and supplies are also included.